

Supplementary material 3 - Summary of study questionnaires and instruments

A. Care map instructions

Making Your Child's Care Map

What is a care map?

A care map shows the people involved in your child's health care and how each person is connected to your child and to each other. An **example** is on **page 3**.

How to make your child's care map

The care map should reflect **how you see** your child's care, who's involved and how they're connected. There is no one way to create a care map. You can draw your own or use the template on page 4. It's up to you. Don't worry about getting it 100% right. If you would like, your child can help you draw the care map.

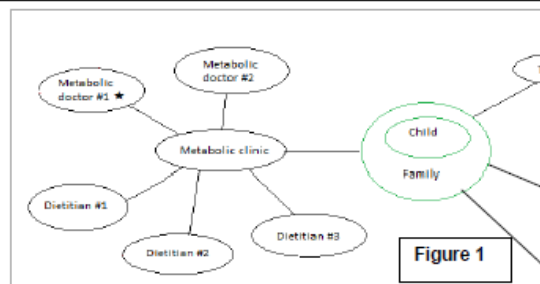
Things to remember

1. **Please do not put your child or other names on the care map.** Use "child," "family" and job titles instead.
2. When adding people or organizations that are part of your child's health care team. Group them together in a way that makes sense to you. See page 5 for examples of people and organizations that you could include. But there can be others!
3. **Try to include the people involved in your child's health care, not just organizations** (e.g. add teacher, Education Assistant, etc instead of just "school").

What if my child sees 2 people with the same job title in the same clinic?

1) Label them Job Title #1, Job Title #2, etc.

2) Decide whether you consider one of them to be the **main "job title"**. If yes, put a star next to Job Title #1. Example: if your child sees 2 metabolic physicians at the metabolic clinic, Dr. Chan, the one your child usually sees, and Dr. Singh, the one you see if Dr. Chan is away, label as follows: "Metabolic Physician #1★" and "Metabolic Physician #2". See Figure 1 below.



4. **Connect providers:** Add lines to connect people or groups who work together for your child's health care, for example, by sharing information, providing or receiving referrals. People can be connected to others in same group or organization or at different groups. (See example, Page 3.)

What if I don't know if 2 people work together or not?

That's OK. Just draw the connections that you know about.

5. **IMPORTANT: Identify up to 10 key providers:** On the Care Map, put the letters "**KP**" next to that person's job title. **Key provider** = someone you think is key to your child's health care. If you do not think any of your child's caregivers is a key provider, just write "No key providers." (See example, Page 3.)

Once you are finished the care map

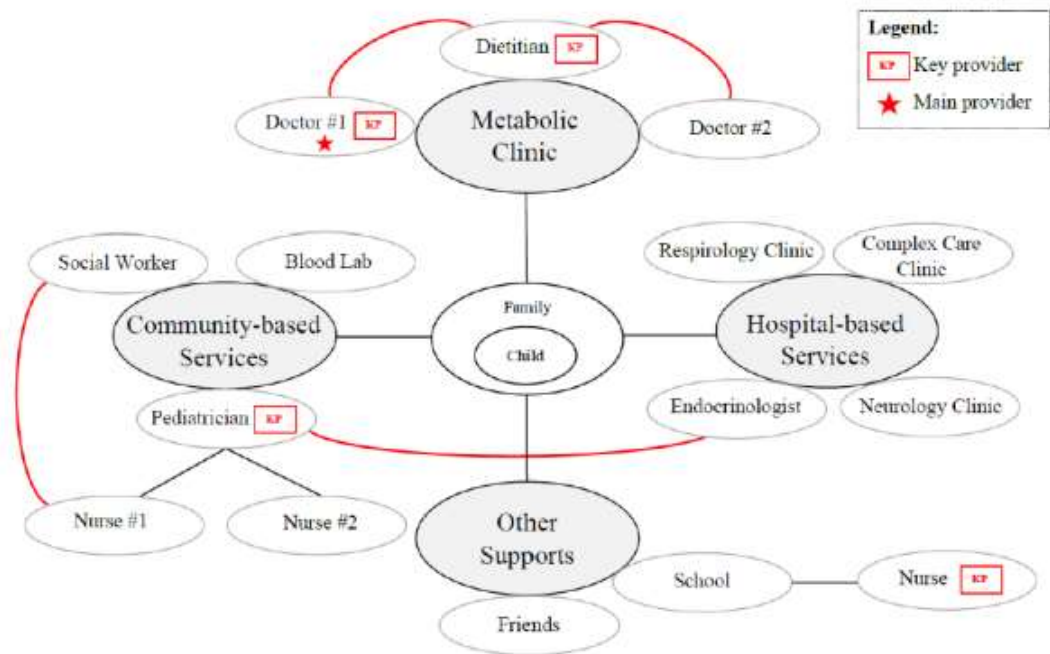
1. **Take a picture** of the care map or **save as a PDF** file. Make sure it is readable in the image.
2. To **upload the picture**, follow the steps in the email we sent you with this document. Please do not email the picture to the study team.
3. We will make a digital version of your care map. We will send you a link to view it and make sure that it is correct.

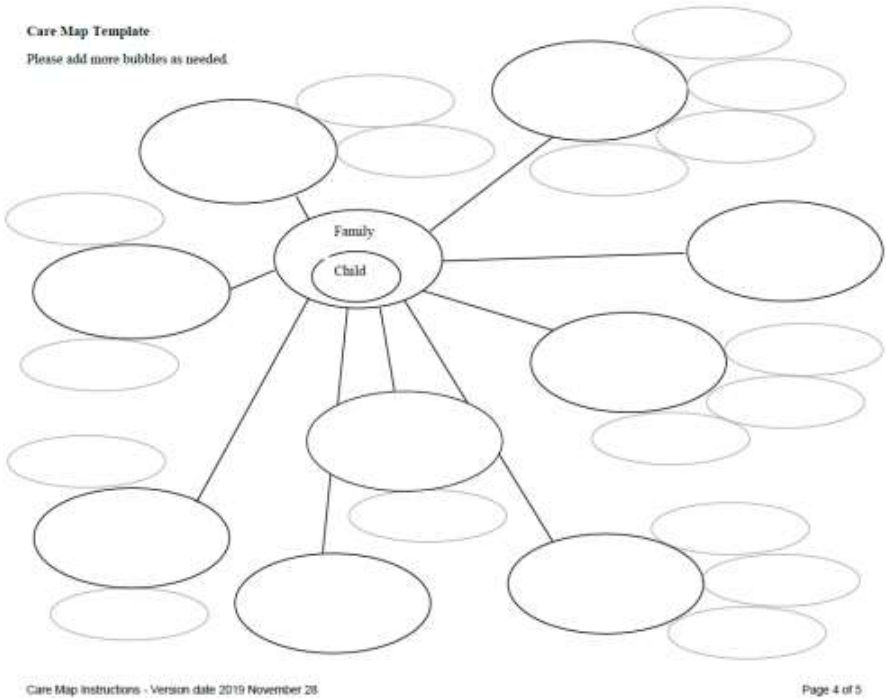
Questions?

If you have any questions while creating or uploading your care map, please **contact Andrea Chow**, study coordinator, at **(613) 562-5800 x4353**, or by email at achow@uottawa.ca.

Instructions adapted from: Antonelli, RC and Lind, C. Care Mapping: A How-To Guide for Patients and Families, <http://www.childrenshospital.org/-/media/Care-Coordination/CareMappingforfamilies21813.ashx?la=en&hash=D8C02FCA893C9A29C939613532334E07127BF9E6>. Accessed September 8, 2017.

Care Map Example





EXAMPLES	SETTINGS – IN HOSPITAL CONTINUED	JOB TITLES CONTINUED
SETTINGS – IN HOSPITAL <u>Specialty Clinics</u> Audiology or Speech Therapy Clinic Cardiology Clinic Complex Care Clinic Dental Clinic Dermatology Clinic Ear Nose Throat Clinic Endocrinology Clinic Gastroenterology Clinic Hematology Clinic Metabolic Clinic Nephrology Clinic Neurology Clinic Optometry / Ophthalmology Clinic Orthodontics Clinic Orthopedic Clinic Pediatrician's Clinic Physiotherapy Clinic Psychology / Psychiatry Clinic Rehabilitation Clinic Respirology Clinic Rheumatology Clinic Urology Clinic <u>Other</u> Ambulatory or Day Unit Emergency Department Feeding or Nutrition Clinic Genetics Unit ICU Inpatient Unit Laboratory Mental Health / Counselling Services NICU Palliative Care Unit Urologist Radiology Unit	 Sleep Clinic Social Work Unit SETTINGS - IN COMMUNITY Blood Lab Clinic Community Centre Daycare Diagnostic Imaging or other Laboratory Hospice Primary Health Care Clinic School Sleep Clinic Walk-in or Urgent Care Clinic Your Home JOB TITLES Acupuncturist Audiologist Behavioural therapist Cardiologist Care coordinator Chiropractor Complex care doctor Counsellor Critical care doctor Dentist Dermatologist Dietitian Doctor Ear nose throat doctor Educational Assistant Endocrinologist Family doctor	 Gastroenterologist Genetic counsellor Geneticist Hematologist Homeopath Lab technician Massage therapist Mental health professional Metabolic doctor Naturopathic doctor Nephrologist Neurologist Nurse Nurse practitioner Occupational therapist Ophthalmologist Optometrist Orthodontist Orthopaedic doctor Palliative care doctor Paramedic Personal support worker Pediatrician Pharmacist Pharmacy assistant Pharmacy technician Physical therapist Physiotherapist Psychiatrist Psychologist Respirologist Rheumatologist Social worker Speech therapist Surgeon Therapist

B. Care map questionnaire

For each key provider identified on the Care Map, the following two questions are asked:

Question	Response options
How well does each of your child's key Health Care Providers know your child?	5-point Likert type scale
How well do you think your child's key health care providers coordinate your child's care with other providers?	5-point Likert type scale

C. Baseline questionnaire

Participants first complete either the **Child Health Questionnaire (CHQ-PF-50)** (if child age ≥ 5) or the **Infant Toddler Quality of Life Questionnaire (ITQOL-SF-47)**, followed by author-developed questions, below:

Question	Response options
Your participating child	
What type of inherited metabolic disease does your child have?	Select one from list
What sex was your child assigned at birth?	Select one from list
In which province or territory does your family live?	Select one from list
At which metabolic clinic does your child currently receive the most care?	Select one from list
Does your participating child have any OTHER chronic illness or special needs?	Yes / No
Yes: To what extent do your participating child's special needs and/or chronic illnesses NEGATIVELY affect your family's emotional well-being?	Select one from list
Has your participating child had a major medical event or health crisis in the past two months?	Yes / No
Your child's caregivers	
INCLUDING YOU, how many primary caregivers does the participating child have?	Select # from list
<i>For each caregiver:</i>	
What is your relationship to your participating child?	Select one from list
What gender do you identify with most?	Select one from list
What is the highest level of education that you have COMPLETED?	Select one from list
What is your CURRENT employment status for paid work?	Select one from list
Are you or have you ever been a landed immigrant, permanent resident, or refugee to Canada?	Yes / No
Yes: In what YEAR did you first become a permanent resident, landed immigrant, or obtain refugee status in Canada?	Year
Participant completes the Carer QOL-7D	
Does your child have any secondary, UNPAID caregivers?	Yes / No
Yes: How many secondary UNPAID caregivers does your child have?	Select # from list
Does your child have any PAID caregivers?	Yes / No
Yes: How many paid caregivers does your child have?	Select # from list
Other members of your household	
Besides your participating child, how many children under the age of 18 live in your household ALL or SOME of the time?	Select # from list
1 or more: Besides your participating child, how many of the other 2 children in your household have the same inherited metabolic disease as your participating child?	Select # from list
Besides your participating child, do any of the OTHER [#] children in your household have any other chronic illness or special needs?	Yes / No
Yes: How much do the special needs and/or chronic illnesses of your OTHER child(ren) affect your family's resources (physical, financial, time, emotional, etc)?	Select one from list

Besides your participating child, have any of your OTHER [#] child(ren) had a major medical event or health crisis in the past two months?	Yes / No
Do any of your [#] other children help to care for your participating child?	Yes / No
Yes: How many of the other # children in your household help to care for your participating child?	Select # from list
Managing the Inherited Metabolic Disease	
COVID-19 has changed the way that health care is provided. In general, how do you feel about the quality of your child's health care since the start of the pandemic (i.e., March 2020)?	5-point Likert type scale
Has your child been diagnosed with COVID-19?	Yes / No
Yes: When did they receive the diagnosis?	Month + year
Since then, have they needed extra health care because of their COVID-19 diagnosis?	Yes / No
Right now, do they still need extra health care because of their COVID-19 diagnosis?	Yes / No
How much do you agree/disagree with each statement for your child?	Matrix
Because of my child's COVID-19 diagnosis...	
...My child's well-being is worse	5-point Likert type scale
...My well-being is worse	5-point Likert type scale
...The well-being of other family member(s) besides me/my child is worse	5-point Likert type scale
Has anyone else in your family been diagnosed with COVID-19?	Yes / No
Over the past 6 months, how have the changes to health care and other services due to the pandemic affected your child's health care?	Check all that apply: 1, One or more of my child's health care appointments or services were cancelled 2, One or more of my child's health care appointments or services were delayed 3, One or more of my child's health care appointments were changed from in-person to virtual (e.g., phone, video) 4, I could not get to the lab, test centre, or pharmacy because their opening hours were reduced 5, Only one primary caregiver was allowed to go with my child to a health care encounter 0, None of the above
Because of the pandemic...	
Checked any 1 – 5: Over the past 6 months, how have these changes to health care services due to the pandemic affected your child's CURRENT health or well-being?	Check all that apply
Because of the pandemic...	
Checked 1: What services or therapies were cancelled?	Check all that apply
Checked 2: What services or therapies were delayed?	Check all that apply
Checked 3: Overall, how did the virtual appointment(s) compare to similar in-person appointments before the pandemic (i.e., March 2020)?	5-point Likert type scale
Checked 3: Compared to similar in-person appointments before the pandemic (i.e., March 2020)...	Matrix
...the virtual appointment(s) were _____.	Shorter the same longer
...on the day of the virtual appointment(s), the wait for the provider was usually _____.	Shorter the same longer
...scheduling the virtual appointment(s) was _____.	Easier the same harder
...communicating with the provider during the virtual appointment(s) was _____.	Easier the same harder
...keeping my child comfortable during the virtual appointment(s) was _____.	Easier the same harder
...understanding what steps would take place after the virtual appointment(s) was _____.	Easier the same harder

<i>Checked 3:</i> How was your privacy during the virtual appointment(s), compared to similar in-person appointments before the pandemic (i.e., March 2020)?	Select one from list
<i>Checked 3:</i> Did you feel more or less involved in decision-making about your child's health during the virtual appointment(s), compared to similar in-person appointments before the pandemic (i.e., March 2020)?	Select one from list
<i>Checked 3:</i> Compared to similar in-person encounters before the pandemic (i.e., March 2020), how much do you agree with the following statements?	Matrix
It was convenient to avoid travelling.	5-point Likert type scale
We were able talk to more than 1 provider at the same time.	5-point Likert type scale
The treatment was less effective.	5-point Likert type scale
It cost us less (out-of-pocket costs).	5-point Likert type scale
<i>Checked 3:</i> If the virtual appointment(s) were different in other ways compared to in-person appointments that took place before the pandemic (i.e., March 2020), please describe in the space below.	Open text
How much do you agree/disagree with each statement for your child?	Matrix
Because of the pandemic...	
...I avoided bringing my child to the emergency department or other parts of the hospital for treatment or care	5-point Likert type scale
...I avoided bringing my child to our primary care provider for treatment or care	5-point Likert type scale
...I had a hard time getting my child's medication or medical products	5-point Likert type scale
Because of the pandemic, I do not want my child to have in-person medical appointments	5-point Likert type scale
I worry about my child getting COVID-19	5-point Likert type scale
Compared to other children, my child is more at risk for COVID-19 complications because of their IMD	5-point Likert type scale
During the pandemic, I have taken public transportation or shared car services to take my child to in-person medical appointments. This has caused me stress or anxiety	5-point Likert type scale
During the pandemic, getting other health care-related needs for my child (e.g., supplies, medication) has caused me stress or anxiety	5-point Likert type scale
During the pandemic, managing my child's IMD at home has been more difficult	5-point Likert type scale
Since the start of the pandemic (i.e., March 2020), how has the pandemic affected your family?	Check all that apply
Do you have a plan, protocol or written directions from the metabolic clinic for managing your participating child's metabolic disease (e.g. a sick day protocol)?	Yes / no
OVER THE PAST 12 MONTHS, what types of treatments, therapies, services, products or equipment have you used to manage your child's inherited metabolic disease?	Check all that apply; specify further
<i>For each item checked:</i>	
OVER THE PAST 12 MONTHS, how hard was it to get [treatment, therapy, service, product, equipment]?	4-point Likert type scale
OVER THE PAST 12 MONTHS, did you get ENOUGH of [treatment, therapy, service, product, equipment]?	Got enough Did not get enough
How difficult is it for you to manage this aspect of your child's care at home?	4-point Likert type scale
OVER THE PAST 12 MONTHS, were there services, therapies or products that your child needed to manage their IMD that you could not get WHEN they needed it?	Check all that apply
<i>For each item checked:</i>	
Why were the necessary medication or drugs not available when needed? Were the reasons:	Financial Non-financial Both
<i>Financial or both:</i> Please specify the FINANCIAL reasons why the [items] were not available.	Check all that apply
<i>Non-financial or both:</i> Please specify the NON-FINANCIAL reasons why the [items] were not available.	Check all that apply

Over the past 3 months, how much time has your family (ALL TOGETHER) spent talking/writing to insurance companies or government agencies about health insurance coverage or reimbursement for medical products?	Select time band from list
<i>If medical diet products used:</i> Where do you TYPICALLY order your child's medical diet products (e.g. formula, supplements, medications, special foods) from?	Check all that apply
How do you typically RECEIVE your child's medical diet products?	Select one from list
How much time PER WEEK on average do you spend on getting medical diet products for your child (including ordering and pick up time)?	Select time band from list
Overall, how satisfied are you with the process of getting special diet products for your child?	5-point Likert type scale
Is there anything in particular that you like or dislike about your typical experiences with getting medical diet products? (Optional)	Open text
Does your family need to spend extra time planning and preparing special meals because of your child's inherited metabolic disease?	Yes / no
How much EXTRA time per WEEK on average does your family spend planning and preparing meals because of your child's inherited metabolic disease?	Select time band from list
<i>If devices or therapies used, for each device or therapy:</i>	
How much time PER WEEK on average does your family spend helping your child?	Select time band from list
Support services for family members	
OVER THE PAST 12 MONTHS, what type of support services for FAMILY MEMBERS have you used?	Check all that apply
<i>For each service used:</i>	
OVER THE PAST 12 MONTHS, how hard was it to get [service]?	4-point Likert type scale
OVER THE PAST 12 MONTHS, did you get ENOUGH of [service]?	Got enough Did not get enough
Who helped your family to access [service] or told you about the service?	Check all that apply
OVER THE PAST 12 MONTHS, are there family support services that your family needed that you could not get WHEN you needed it?	Check all that apply
The impact of the inherited metabolic disease on caregivers' paid work outside the home	
OVER THE PAST 12 MONTHS, how many DAYS in TOTAL have your child's primary caregivers missed paid work due to caring for your participating child, for any reason?	Select one from list
Have any of your child's primary caregivers ever LEFT or QUIT a job because of your child's inherited metabolic disease?	Yes / no
Have any of your child's primary caregivers ever had to REDUCE their paid work hours because of your child's inherited metabolic disease?	Yes / no
The financial impact of the inherited metabolic disease on your family	
Over the past 12 months, what was your TOTAL household income before tax (Canadian dollars)?	Select one from list
OVER THE PAST 12 MONTHS, did you have to buy any products (including medical foods and formulas), devices, supplies, equipment or household items in order to manage your child's inherited metabolic disease?	Yes / no
<i>If yes:</i> How much, in Canadian dollars, did your family pay <u>out of pocket</u> to buy these products in the past 12 months?	Select one from list
OVER THE PAST 12 MONTHS, did you need to make any permanent or temporary modifications or renovations to your home to accommodate your child's inherited metabolic disease?	Yes / no
<i>If yes:</i> How much, in Canadian dollars, did your family pay <u>out of pocket</u> to modify or renovate your home in the past 12 months to accommodate your child's inherited metabolic disease?	Select one from list
<i>If yes to either question re: purchase of products / home modifications:</i> How difficult was it for your family to afford these recent costs (home modifications and/or products)?	Select one from list
Pharmacy encounters	

In the past 6 months, how often did your family visit the pharmacy to pick up <u>prescribed</u> medications, foods, formulas or products for your participating child?	Select one from list
<i>If more than once a week:</i> In the past 6 months, how many different pharmacies did you visit?	Select one from list
<i>If once or more:</i>	
Where was the pharmacy (or pharmacies) located?	In Hospital / in community
ACCESS TO CARE Thinking about your visits and interactions with the pharmacy over the past 6 months, how much do you agree with the following statements:	
The medication or medical products typically arrived in the right formulation, supply amount, and in appropriate containers.	5-point Likert-type scale
The typical length of time between ordering the medication/medical products and picking them up was acceptable.	5-point Likert-type scale
The typical amount of time it takes to travel to the pharmacy was acceptable.	5-point Likert-type scale
Overall, how satisfied were you with your child's typical access to care at the pharmacy?	5-point Likert-type scale
Was there anything that you particularly liked or disliked about your child's typical access to care at the pharmacy? (Optional)	Open text
RESPECT FOR YOUR CHILD & FAMILY	
Overall, how satisfied were you with the respect that the pharmacist and/or staff typically showed you and your child over the past 6 months?	5-point Likert-type scale
Was there anything that you particularly liked or disliked about the respect that the pharmacy team typically showed you? (Optional)	Open text
COORDINATION OF CARE	
Thinking about your visits and interactions with the pharmacy over the past 6 months, how much do you agree with the following statements:	
Typically, the pharmacy team seemed to agree with each other about my child's treatment.	5-point Likert-type scale
Typically, the pharmacy team and providers at other locations coordinated my child's treatment appropriately.	5-point Likert-type scale
Did the metabolic clinic give you a letter about your child's inherited metabolic disease to share with the pharmacy?	Yes / no
Overall, how satisfied were you with the way that the pharmacy team typically coordinated your child's care?	5-point Likert-type scale
Was there anything that you particularly liked or disliked about the way that the care provider(s) typically coordinated your child's care? (Optional)	Open text
INFORMATION SHARING	
Overall, how satisfied were you with the typical information sharing by the pharmacy team over the past 6 months?	5-point Likert-type scale
Was there anything that you particularly liked or disliked about the typical information sharing by the pharmacy team? (Optional)	Open text
FAMILY INVOLVEMENT	
Overall, how satisfied were you with your family's typical involvement in your child's care at the pharmacy?	5-point Likert-type scale
Was there anything that you particularly liked or disliked about your family's typical involvement in your child's care at the pharmacy? (Optional)	Open text
FOLLOW UP AND CONTINUITY OF CARE	
Thinking about your visits and interactions with the pharmacy over the past 6 months, how much do you agree with the following statements:	
Typically, I got enough written information from the pharmacy about possible side effects of any new medications or any other new information I needed to take care of my child at home.	5-point Likert-type scale
Typically, I knew what to do or whom to call if I had any questions after leaving the pharmacy.	5-point Likert-type scale
Overall, how satisfied were you with the typical follow-up and continuity of care after visits to the pharmacy?	5-point Likert-type scale
Was there anything that you particularly liked or disliked about the typical continuity of care and follow-up after visits to the pharmacy? (Optional)	Open text

OVERALL IMPRESSIONS OF THE PHARMACY	
Overall, how satisfied were you with your typical experiences with the pharmacy over the past 6 months?	5-point Likert-type scale
Is there anything else that you particularly liked or disliked about your typical experiences with the pharmacy? (Optional)	Open text

Indented questions are branched – only appear if specified responses to previous question(s) selected

D. Pre-questionnaire for the weekly diaries – sample questions

Question	Response options
Does your family do blood draws at home as part of managing your child's health?	Yes / no
<i>If yes:</i> How often do you and your child do blood draws at home?	Select one from list
Typically, what type of health care providers do you and your child interact with while getting the supplies, doing the blood draw, sending the sample, and waiting for and getting results?	Check all that apply
Where do you typically get the lancets you need for the blood draws?	Check all that apply
Considering your and your child's TYPICAL experience of doing blood draws at home, how much do you agree with the following statements:	
ACCESS TO CARE	
It is easy to get the items that we need to do the blood draws.	5-point Likert-type scale
If I have questions or concerns about doing a blood draw, I am able to contact the right care provider in a timely manner.	5-point Likert-type scale
The method we have to use to send the blood samples to the lab is acceptable (i.e. send by post, drop off in person).	5-point Likert-type scale
PHYSICAL COMFORT	
I receive enough support from the health provider(s) to make my child as physically comfortable as possible (i.e. to handle physical pain or discomfort) during the blood draw(s).	5-point Likert-type scale
EMOTIONAL SUPPORT	
If I share any concerns with the health care providers or staff, they respond appropriately.	5-point Likert-type scale
If my child shares any concerns with the health care providers or staff, they respond appropriately.	5-point Likert-type scale
We can do blood draws at a convenient time of the day for my family.	5-point Likert-type scale
I am comfortable drawing the blood from my child at home.	5-point Likert-type scale
INFORMATION SHARING	
I am able to share the information that I want to share about my child's blood draws with relevant provider(s).	5-point Likert-type scale
If I share information about my child's health, the care providers listen to what I have to say and respond appropriately.	5-point Likert-type scale
A care provider gives me information that I can understand about how to do the blood draw(s) at home, including getting supplies, doing the blood draw(s), and sending blood samples to the lab.	5-point Likert-type scale
A care provider gives me as much information as I want about the blood test results and clearly explains any recommendations for follow up.	5-point Likert-type scale
FOLLOW UP OF CARE	
The method that the clinic uses to send us the results of the blood tests is acceptable.	5-point Likert-type scale
The wait time for results from the blood tests is acceptable.	5-point Likert-type scale
Typically, how many days do you wait between sending the sample and receiving the results of the tests done on the blood draw?	Select one from list
YOUR FAMILY'S TIME INPUTS & FINANCIAL IMPACTS	
Typically, how much time do you and your child spend on EACH blood draw?	Select one from list

Typically, do any of your child's caregivers have to take time off paid work to do a blood draw at home?	Yes / no
<i>If yes:</i> Typically, how much time off from paid work do your child's caregivers need to do a blood draw at home?	Select one from list
Does your family typically have any financial expenses that you have to pay directly because of, or related to, the blood draws you do at home, even if you are later reimbursed by an insurance plan?	Yes / no
<i>If yes:</i> What financial expenses does your family typically have?	Check all that apply
How much do you typically have to pay out of pocket and will NOT be reimbursed by a provincial or private insurance plan?	Select one from list
How much do you agree with this statement: The financial expenses related to doing blood draws at home typically cause me stress or anxiety.	5-point Likert-type scale

Indented questions are branched – only appear if specified responses to previous question(s) selected

E. Weekly diaries – sample questions

Question	Response options
Did your child receive any medical health care in Canada between [start_date] and [end_date]?	Yes / no
<i>If yes:</i> What types of health care encounter(s) did your child have during this week?	Check all that apply
FOLLOW-UP ON RECENT TESTS (if applicable)	
Did you expect a care provider to discuss the results of a medical test that your child had last week, in person, by phone or by e-mail?	Yes / no
<i>If yes:</i> With whom were you expecting to discuss the test results?	Select one from list
What type of test(s) were you waiting for the results of?	Check all that apply
How many days did you wait for a care provider to discuss the results for [test] with you?	Select one from list
How much do you agree with the following statement: The wait time for the [test] results was acceptable.	5-point Likert-type scale
How much do you agree with the following statement: A care provider gave me as much information as I wanted about the [test] results and clearly explained any recommendations for follow-up.	5-point Likert-type scale
<i>If still waiting:</i> How many days have you waited so far for a care provider to discuss the results for [test] with you?	Select one from list
How much do you agree with the following statement: The wait time so far for the [test] results is acceptable.	5-point Likert-type scale
How much do you agree with the following statement: A care provider gave me as much information as I wanted about where, when, and how I will get the [test] results.	5-point Likert-type scale
COVID-19	
Did your child get a COVID-19 test between [start_date] and [end_date]?	Yes/no
Was your child diagnosed with COVID-19 between [start_date] and [end_date]?	Yes/no
Were any health care encounters originally scheduled between [start_date] and [end_date] cancelled or delayed by the clinic or provider?	Yes/no

Between [start_date] and [end_date], did you avoid seeking care for a health concern for your child due to the pandemic?	Yes/no
<i>For every in-person encounter (questions and responses tailored to each care setting):</i>	
Where did you and your child have this IN-PERSON care encounter?	At the Hospital / in community
<i>Hospice or palliative care unit:</i> Did your child stay overnight?	Yes/no
Was this encounter unplanned or pre-planned?	Select one from list
Were you and your child familiar with this place (e.g. clinic, lab, Hospital unit)?	Yes/no/somewhat
Was this place (e.g. clinic, lab, Hospital) in your province or territory of residence?	Select one from list
When did this encounter take place?	Date
During this care encounter, what type of health care provider(s) did you or your child see or communicate with?	Check all that apply
<i>For each checked provider:</i> Was this health care provider familiar with your child?	Yes/no/somewhat
Was this health care provider (or each of these health care providers or staff) familiar with your child's IMD?	Yes/no/somewhat
<i>Lab:</i> What type of tests did your child have during this encounter?	Check all that apply
<i>If the participant identified this encounter's setting as a place where their child has frequent encounters in the Pre-Questionnaire for the weekly diaries:</i>	
COMPARING THIS ENCOUNTER TO YOUR TYPICAL ENCOUNTERS	
Was this encounter the SAME as your typical encounters at [setting] in the following ways:	Check all that apply
The time you typically spend on encounters at [setting]: [participant response on Pre-Questionnaire]	
How long it took you to travel to the [setting]: [participant response on Pre-Questionnaire]	
Whether you or any of your child's other caregivers typically need to take time off paid work for encounters at [setting]: [participant response on Pre-Questionnaire]	
The time off paid work that you or any of your child's other caregivers typically need to take for encounters at [setting]: [participant response on Pre-Questionnaire]	
Whether your child typically misses school for encounters at [setting]: [participant response on Pre-Questionnaire]	
The time away from school that your child typically needs for encounters at [setting]: [participant response on Pre-Questionnaire]	
Your response to the statement "We are usually able to go to the [setting] at a convenient time in the day for our family": [participant response on Pre-Questionnaire]	
The time your child typically spend on encounters at [setting] (including arranging, the actual encounter, and any follow-up): [participant response on Pre-Questionnaire]	
<i>For any aspect unchecked, the participant is asked about the aspect for this encounter.</i>	

Tests at the hospital laboratory (during overnight stays at the hospital, if applicable)	
During this hospital stay, did your child leave the [setting] to go to another area of the Hospital for medical testing? (e.g. radiology, imaging, diagnostics)	Yes/no
Yes: Did you or another caregiver go with your child when they had these tests?	Yes, always/yes, sometimes/no
<i>If yes, always or sometimes:</i> What type of tests did your child have outside the [setting]?	Check all that apply
Considering ALL your child's visits to labs for medical testing during their stay at the [setting], how much do you agree with the following statement: We did not wait too long in the lab's waiting room.	5-point Likert-type scale
Considering ALL your child's visits to labs for medical testing during their stay at the [setting], how much do you agree with the following statement: At the lab, information about the test process was shared with me in a way that I could understand.	5-point Likert-type scale
Considering ALL your child's visits to labs for medical testing during their stay at the [setting], how much do you agree with the following statement: At the lab, age-appropriate information about my child's test process was shared with my child in a way that THEY could understand.	5-point Likert-type scale
Considering ALL your child's visits to labs for medical testing during their stay at the [setting], how much do you agree with the following statement: If my child had physical pain or discomfort during the test process, the lab's care provider(s) took the concern seriously and tried to address it.	5-point Likert-type scale
Considering ALL your child's visits to labs for medical testing during their stay at the [setting], how much do you agree with the following statement: If my child had physical pain or discomfort during the test process, the lab's care provider(s) respected my family's knowledge about how to make my child more comfortable.	5-point Likert-type scale
Considering ALL your child's visits to labs for medical testing during their stay at the [setting], how much do you agree with the following statement: If my child or I shared any concerns with the lab's health care providers or staff, they responded appropriately.	5-point Likert-type scale
Access to care	
How much do you agree with the following statements:	
We were able to schedule the encounter to take place at a convenient time in the day for my family.	5-point Likert-type scale
The length of time between getting a referral or scheduling the encounter and the date of the encounter was acceptable.	5-point Likert-type scale
The time it took to travel to the encounter was acceptable.	5-point Likert-type scale
We did not wait too long in the waiting room.	5-point Likert-type scale
The time spent waiting for the care provider was acceptable	5-point Likert-type scale
I was able to meet with the provider(s) I needed to talk to about my child's care.	5-point Likert-type scale
I (and/or my child) spent enough time with the health care provider(s).	5-point Likert-type scale
How long did it take you to travel from your home to this encounter?	Select one from list
Was this care encounter re-scheduled from a previous time that was cancelled or postponed?	Yes/no
Who cancelled or postponed the original encounter?	Select one from list

Overall, how satisfied were you with your child's access to care for this encounter?	5-point Likert-type scale
Was there anything that you particularly liked or disliked about your child's access to care during this encounter? (Optional)	Open text
Coordination of care	
Did the metabolic clinic provide your family with an emergency department letter?	Yes/no
Yes: Did you share the letter with health care providers or staff at the Emergency Department?	Yes/no
How much do you agree with the following statements:	
During this health care encounter, an Emergency Department health care provider or staff read the letter and responded appropriately.	5-point Likert-type scale
During this health care encounter, the care providers seemed to work together.	5-point Likert-type scale
During this health care encounter, the care providers seemed to agree with each other about my child's care or treatment.	5-point Likert-type scale
Health care providers that we saw during this encounter and health care providers at other locations coordinated my child's care appropriately.	5-point Likert-type scale
Overall, how satisfied were you with the way that the care provider(s) coordinated your child's care during this encounter?	5-point Likert-type scale
Was there anything that you particularly liked or disliked about the way that the care provider(s) coordinated your child's care during this encounter? (Optional)	Open text
Information sharing	
How much do you agree with the following statements:	
During this health care encounter (including during preparing for the encounter and any follow-up)...	
...information was shared with ME in a way that I could understand.	5-point Likert-type scale
...age-appropriate information about my child's treatment was shared with MY CHILD in a way that they could understand.	5-point Likert-type scale
...I was able to share the information that I wanted to share about my child's care with the provider(s).	5-point Likert-type scale
...if I shared information about my child's health, the care providers listened to what I had to say and responded appropriately.	5-point Likert-type scale
Overall, how satisfied were you with information sharing by health care providers and/or staff during this health care encounter?	5-point Likert-type scale
Was there anything that you particularly liked or disliked about the information sharing by care providers and/or staff during this health care encounter? (Optional)	Open text
Physical comfort	
How much do you agree with the following statements:	5-point Likert-type scale
If my child had physical pain or discomfort during the health encounter...	
...the care provider(s) took the concern seriously and tried to address it.	5-point Likert-type scale

...the care provider(s) respected my family's knowledge about how to make my child more comfortable.	5-point Likert-type scale
Overall, how satisfied were you with the care provider(s)'s efforts to make your child physically comfortable during this encounter?	5-point Likert-type scale
Was there anything that you particularly liked or disliked about the care provider(s)'s efforts to make your child PHYSICALLY comfortable during this encounter? (Optional)	Open text
Emotional support	
How much do you agree with the following statements:	
If I shared any concerns with the health care providers or staff, they responded appropriately.	5-point Likert-type scale
If MY CHILD shared any concerns with the health care providers or staff, they responded appropriately.	5-point Likert-type scale
Overall, how satisfied were you with the health care providers' EMOTIONAL SUPPORT given to you and your child during this encounter?	5-point Likert-type scale
Was there anything that you particularly liked or disliked about efforts made by the health care providers or staff to provide EMOTIONAL support to you and your child during this encounter? (Optional)	5-point Likert-type scale
Family involvement	
Overall, how satisfied were you with your family's involvement in your child's care during this care encounter?	5-point Likert-type scale
Was there anything that you particularly liked or disliked about the care provider(s)'s efforts to involve your family during this encounter? (Optional)	Open text
Respect for your child & family	
Overall, how satisfied were you with the respect that care providers and staff showed you and your child during this encounter?	5-point Likert-type scale
Was there anything that you particularly liked or disliked about the respect that care providers and staff showed you and your child during this encounter? (Optional)	Open text
Follow up and continuity of care	
How much do you agree with the following statements:	
Before the end of this health care encounter, I got enough written information about possible side effects of any new medications, physical limitations, dietary needs or any other new information I needed to take care of my child at home.	5-point Likert-type scale
Before the end of the encounter, a care provider explained in a way that was easy to understand what symptoms or health problems to look out for after the encounter.	5-point Likert-type scale
I knew what to do or whom to call if I had any questions after this health care encounter.	5-point Likert-type scale
I got enough information about the next steps that I needed to take after the encounter. (e.g. booking new appointments, location of follow-up appointments, renewing prescriptions)	5-point Likert-type scale
The care provider(s) took all the steps that I expected them to take after the encounter. (e.g. making referrals, booking new appointments)	5-point Likert-type scale
Overall, how satisfied were you with the continuity of care and follow-up to this encounter?	5-point Likert-type scale

Was there anything that you particularly liked or disliked about the continuity of care and follow-up to this encounter? (Optional)	Open text
Time inputs and financial impacts	
How much time did you and your child spend on this encounter (including arranging, travel if applicable, waiting, and the actual encounter)?	Select one from list
Did your family have any financial expenses that you had to pay directly because of, or in relation to, this care encounter, even if you were later reimbursed by an insurance plan?	Yes/no
Yes: What financial expenses did your family have?	Check all that apply
How much did you have to pay out of pocket and will NOT be reimbursed by a provincial or private insurance plan? Give your best estimate.	Select one from list
How much do you agree with this statement: The financial expenses related to this health care encounter cause me stress or anxiety.	5-point Likert-type scale
Did you or any of your child's other caregivers have to take time off paid work for this care encounter?	Yes/no
Yes: ALL TOGETHER, how much time off paid work did you need for this care encounter?	Select one from list
Did your child miss school/class for this care encounter?	Yes/no
Yes: How much time away from school/class did your child need for this care encounter?	Select one from list
Overall experience	
Overall, how satisfied were you with your and your child's experiences with care during this encounter?	5-point Likert-type scale
Was there anything else that you particularly liked or disliked about your and your child's experiences with care during this encounter? (Optional)	Open text
Compared to similar encounters that took place before the pandemic (i.e., March 2020), was this encounter shorter or longer?	Select one from list
Compared to similar encounters that took place before the pandemic (i.e., March 2020), was the amount of time from when you scheduled the appointment to the date of the appointment shorter or longer?	Select one from list
Did the provider request or tell you that there was a limit to the number of caregivers who could attend the encounter with your child?	Yes/no
Yes: Did this affect who or how many people went to the encounter with your child?	Yes/no
In your opinion, was there any other important difference between this encounter and other ones like it before the pandemic? If yes, please describe below.	Open text
Was this encounter scheduled BECAUSE it was required for a study or trial that your child is taking part in?	Yes/no
Which of your child's caregivers went to this encounter with your child?	Check all that apply
Who contributed to filling out this Experience Questionnaire?	Check all that apply
Which of these people was the MAIN person filling out this questionnaire?	Select one from list
Questions similar to these are also tailored to remote/virtual encounters, and for any blood draws done at home by the family.	

F. Care Map Interview Guide

Overall Network of Care

1. Can you please walk me through your child's network of care?
 - *Probe for specific aspects related to:*
 - Validation of listed providers and connections – is the network accurate as it is or would you like to make any changes to it?
 - The process of drawing the network of care- how did you decide who to include in the network?

Identification of Key Providers

2. You identified [provider X] as a key provider. What are the factors that make them a 'key provider' for (kid's name)?
 - *Probe for specific aspects related to:*
 - From the care map questionnaire, I noticed that you indicated that this provider knows your child very well. What does that look like to you? (how do you know?)
 - How often does (kid's name) interact with the provider?
 - What is the provider's role in the child's care?

Care Coordination

3. You identified that [provider X] and [Provider Y] are connected. Can you tell me about that connection?
 - *Probe for specific aspects related to:*
 - What is the nature of the connection?
 - What is the impact of the connection on the family? How can you tell?
4. On the care map questionnaire, you told us that [provider X] coordinates with other providers "very well."
 - How does provider x work with other providers (e.g., shares information, makes referrals, you don't have to fill them in on Can you tell me about factors that influenced your positive rating?
5. On the care map questionnaire, you told us that [provider X] coordinates with other providers "not well at all."
 - Can you tell me about factors that influenced your negative rating?
 - What could/should be done to improve it?

Adequacy of Network of Care

6. How well does this network of care meet your child's needs? How does this network of care meet your needs?
 - *Probe for specific aspects related to*
 - Are there parts of the network that work better than others? What parts work better? In what ways?
 - What can be improved in this network of care? How could the network be improved to better meet (kid's) needs?
 - Are there people who should be key providers but they are not listed as such? Who and How come?
 - Are there providers who should be connected on your care map but who are not currently connected? Which providers do you think should be connected? How would this help?

G. Encounter Interview Guide

Direct contributors to satisfaction rating

1. You rated your satisfaction with [this encounter / specific Picker Principle] [RATING]. In your view, what made this interaction [positive/negative]?
 - *Probe for specific aspects related to:*
 - Picker Principles
 - Setting
 - Modality

Identification of how negative encounter could have been different

2. *If negative:* In your opinion, what would have made this encounter better for you and your child?
 - *Probe for role of:*
 - Specific providers / teams
 - Specific actions (actor not necessarily important)
3. *For each agent of change:* In your opinion, what could they have done differently?

Identification of HCP who could have helped

4. *If negative:* Is there another health care provider involved in your child's care who you think could have helped in this situation?

Comparison to previous, similar encounters (same mode)

5. Have you been to [setting] before? / Have you met this [provider] before?
 - *If yes:* How did this interaction compare with other interactions you've had [with PROVIDER/at LOCATION]?
 - *If worse or better:*
 - How was it worse/better?
 - Was there anything else different about this encounter than other ones (e.g., longer wait time, different receptionist)?
 - *If the same – negative:* What do you wish would happen instead?

Impact of the encounter

6. How did this interaction affect your child, you, and other members of your family?
 - *Probe for different impacts*, e.g., psychological, physical, emotional, social, financial
 - *If negative:* What / is there anything else that would have made this interaction more positive for you?
 - *If negative and other encounters are the same:* Since you've had other negative experiences [at clinic / with provider], did it change the way you prepared for this encounter?